# Department of Health and Human Services National Institute of Environmental Health Sciences National Cancer Institute

# Minutes of the Research Translation, Dissemination, and Policy Implications Subcommittee of the Interagency Breast Cancer and Environmental Research Coordinating Committee

# November 29, 2011

The Research Translation, Dissemination, and Policy Implications (RTDPI) Subcommittee of the Interagency Breast Cancer and Environmental Research Coordinating Committee (IBCERCC) was convened for a meeting on November 29, 2011 at 3:00 PM EST via conference call. The Chair of the subcommittee was Jeanne Rizzo, R.N. of the Breast Cancer Fund.

#### **Subcommittee Members Present**

Beverly Canin Ysabel Duron Ronda Henry-Tillman, M.D. Karen Miller Marcus Plescia, M.D., M.P.H. Jeanne Rizzo, R.N. Shelia Zahm, Sc.D.

#### **NIH Staff Present**

Dacia Beard, M.P.H. (NCI) Jennifer Collins, M.R. (NIEHS)

#### **Others**

Connie Engle, Ph.D.

## I. BACKGROUND

The Interagency Breast Cancer and Environmental Research Coordinating Committee (IBCERCC) is a congressionally mandated body established by the National Institute of Environmental Health Sciences (NIEHS), in collaboration with the National Cancer Institute (NCI). This Committee is comprised of 19 voting members, including representatives of Federal agencies; non-federal scientists, physicians, and other health professionals from clinical, basic, and public health sciences; and advocates for individuals with breast cancer.

The Committee's primary mission is to facilitate the efficient and effective exchange of information on breast cancer research activities among the member agencies, and to advise the NIH and other Federal agencies in the solicitation of proposals for collaborative, multidisciplinary research, including proposals to further evaluate environmental and genomic factors that may be related to the etiology of breast cancer. The Committee serves as a forum and assists in increasing public understanding of the member agencies' activities, programs, policies, and research, and in bringing important matters of interest forward for discussion.

The objectives of the RTDPI Subcommittee of the IBCERCC are integrated and dependent on the objectives and activities of the other Subcommittees of the IBCERCC and include the following: to identify successful models as well as gaps in research translation and dissemination, to make recommendations to improve both with an emphasis on breast cancer and the environment; to make policy recommendations to that end; to address areas in which the scientific evidence on breast cancer and the environment supports precautionary public health policy; and to identify methods to expand public participation in the research translation and dissemination processes to more effectively involve patient advocacy and community organizations, environmental health, environmental justice as well as practitioners in public health and health care delivery.

The eleventh meeting (conference call) of the RTDPI Subcommittee took place on November 29, 2011. During this meeting, the Subcommittee's draft chapters for the IBCERCC report were discussed.

### II. DISCUSSION

Jeanne welcomed everyone to the call and began by reviewing the agenda for the call.

Jeanne asked NIH staff if they had any additional information regarding the sidebar stories for the report. Jenny reported that Ed Kang at NIEHS has provided some guidance for them and has agreed to compile them for the group. She said that they will start gathering personal stories to highlight the content in the report. During the call she sent some information regarding the format and Ed's contact information. The members of the Subcommittee requested that they be cc'd on stories that are being sent to Ed.

Jeanne asked Jenny if changes have been made since the September meeting to the definition of environment by the other Subcommittees. Jenny reported that to her knowledge there have been no additional edits.

Next, the group reviewed the current version of the Policy Matters chapter. Shelia briefly described the changes that were made including the removal of extraneous verbiage, punching up of the language in some places, the addition of information pertaining to green chemistry, and the addition of policy references.

Shelia walked the group through the document, starting with the current list of the definitions. It was noted that "hazard assessment" should be added to the list of definitions since both "risk" and "risk assessment" are defined. The group also suggested alphabetizing the list of definitions. Beverly noted that the definition for "exposure" needs to be revised a little. She will do this and send to Shelia. The group also thought that citations were needed for the definitions. Finally, it was mentioned that the current definition for "risk assessment" does not include exposures. The suggestion was made to see how EPA defines this term. Connie and Shelia will look into this.

Beverly noted that the introduction end paragraph seems to be missing a comma.

Ysabel mentioned that while underserved populations are mentioned frequently in the document that the group has not captured why this group needs a particular type of attention. During the discussion of this, it was suggested that the definition of environmental justice be added to the list of definitions. Shelia requested that Ysabel send her the material that she previously sent to Michael Gould. Jeanne inquired as to whether Michael's group planned to use the material. Jenny was uncertain. Jeanne suggested including here to make sure it was not lost. If it is repeated, we can edit later.

With regard to the recommendation for this section, Jeanne wondered if the current text has enough information on radiation. Shelia suggested that this fits best in the environmental monitoring and risk assessment sections.

The story of DES that Jeanne has might make a good sidebar story in Section 1.

The monitoring of equipment, in addition to people's lifetime exposure, needs to be added to the recommendation for section 2.

For section 3, it was noted that the citation for the 2010 APHA statement on EDCs should be included. Ysabel also noted that race and economic conditions are not captured in this section.

Information from the Research Process subcommittee is needed for section 4.

For the recommendation for section 5, it was noted that it should be "advocates and community representatives". Also, the work "adequately" should be changed to "fairly". Beverly noted that the ongoing work of the agencies should be recognized in the text by changing "agencies should establish" to "agencies should continue or establish".

The group mentioned the use of Linda's wording regarding the precautionary principle. The group will find her wording and add it back to the document.

Shelia will make the recommended changes and then send back to Connie.

Next the group moved on to discuss the merged research translation, dissemination and communications chapter. The current header for the chapter is "From Science to Society". It was suggested that the header for the policy chapter be "From Science to Action".

As with the policy chapter, the group went through the chapter, starting with the definitions. They will be alphabetized as in the other chapter. Beverly will edit the definition of "advocate" and send to Connie.

The group expressed concern for the way the chapter reads. It seems to be at a high level. It was noted that there is a lot of redundancy here and that removal of the redundancy will make the chapter more readable. The group felt that another set of eyes was needed for reviewing the chapter.

The group discussed the placement of the recommendations in the chapter. One suggestion was to include the recommendations that span the scope of the entire chapter at the beginning of the chapter. In addition, secondary recommendations specific to 1) research translation; 2) research dissemination; and 3) research communication would follow each of the key sections. Connie will reorganize based on this suggestion.

Beverly requested that we not use the terms "human girls".

The group discussed two areas of the chapter that reflected substantive additions since the last revision – the section on research ethics, which was expanded to include the precautionary principle and report-back to study participants and the section identifying features of existing programs. Ysabel requested that a statement be added to the ethics section on report-back that discussed historical reasons for mistrust of research projects among some communities. Connie will address this. The team expressed that the additions to the section on features of existing programs was now much stronger due to expanded and specific examples of the highlighted characteristics of strong programs. The team agreed that these changes met the goals of the matrix presentation of the same material and that the current narrative draft could not have reached this point without the work on the matrix.

The group concluded by discussing the timeline that has been developed and whether it was a timeline for breast cancer advocacy or a timeline for breast cancer and the environment. The group views the timeline as a roadmap with several lanes. There can be lanes for advocacy, scientific findings, and policy/legislation. Jenny noted that the progress list that the SOS subcommittee is developing will not have dates associated with it. Jeanne said that she will bring up the timeline on the call with the Chairs. Jenny will send Beverly the progress table that the SOS subcommittee is developing and the timeline that Debbie sent her. Kathy also requested that this information be sent to her.

### **Action Items:**

- Jenny will send the group additional guidance regarding the sidebars as it becomes available.
- Shelia will incorporate changes recommended during the call for the policy chapter and send the revised document to Connie.
- Beverly will edit the definition of "advocate" and send to Connie.
- Connie will incorporate the changes recommended during the call for the merged chapter.
- Jeanne will bring up the timeline discussed today (roadmap) on the call with the Chairs.
- Jenny will send Beverly and Kathy the progress table that the SOS subcommittee is developing and the timeline that Debbie sent her. Kathy also requested that this information be sent to her.

# **CERTIFICATION**

I hereby certify that, to the best of my knowledge, the foregoing minutes and attachments are accurate and complete.

## /Jeanne Rizzo/

Jeanne Rizzo, RN

Chairperson

Research Translation, Dissemination, and Policy Implications Subcommittee Interagency Breast Cancer & Environmental Research Coordinating Committee

### /Gwen W. Collman/

Gwen W. Collman, PhD

**Executive Secretary** 

Research Process Subcommittee

Interagency Breast Cancer & Environmental Research Coordinating Committee

Proper signatures

Treat as signed,  $\S 1.4(d)(2)$